



4191-02U

SOCIAL SECURITY ADMINISTRATION

[Docket No. SSA-2013-0054]

Open Government: Use of Genetic Information in Documenting and Evaluating Disability; Extension of Comment Period

AGENCY: Social Security Administration.

ACTION: Notice of extension of comment period.

SUMMARY: On November 26, 2013, we announced in the Federal Register that we were soliciting ideas and comments about the use of genetic information in the disability determination process via an online forum. We stated that the forum would be open until December 26, 2013. We are extending that deadline until January 16, 2014.

DATES: The forum will be open for your ideas and comments until January 16, 2014.

FOR FURTHER INFORMATION CONTACT: Cheryl A. Williams, Office of Medical Listings Improvement, Social Security Administration, 6401 Security Boulevard, Baltimore, Maryland 21235-6401, (410) 965-1020. For information on eligibility or filing for benefits, call our national toll-free number, 1-800-772-1213, or TTY 1-800-325-0778, or visit our Internet site, Social Security Online, at <http://www.socialsecurity.gov>.

SUPPLEMENTARY INFORMATION:

On November 26, 2013, we announced in the Federal Register that we were soliciting ideas and comments about the use of genetic information in the disability determination process via an online forum that would be open until December 26, 2013.¹ We have decided to extend that deadline until January 16, 2014.

We would like the public's ideas and comments regarding how we should use genetic information within the disability decision process. Under our current, long-standing policy, we do not purchase genetic testing to evaluate disability. However, we do consider all evidence in the record, including genetic testing and other genetic medical evidence, when we make a determination or decision of whether you are disabled.²

We solicited the public's ideas and comments on the use of genetic information in order to obtain innovative ideas that we could use to improve the disability determination process. Your comments are important to us and we encourage you to share your ideas on any and all related issues. Some of the specific issues we would like information on include:

- What role should genetic specialists have in providing medical evidence?;
- Should we use direct-to-consumer genetic test results, and if so, how should we use those results?;
- How useful is genetic information in determining prognosis and progression of an impairment?;
- What role should genetic information have in the continuing disability review process?;

¹ 78 FR 70617.

² 20 CFR 404.1512-404.1513, 404.1520, 416.912-416.913, and 416.920.

- Can we make determinations regarding known genetic conditions in the absence of genetic test results, and if so, how should we do so?;
- What privacy safeguards should we apply when we obtain and use genetic information?; and
- Are there any related issues that may inform our future policies?

How to Participate

The forum is open to all members of the public. To submit your ideas and comments, please go to <http://www.ssa-disabilityideas.ideascale.com> and go to the Campaign entitled "Genetic Information." You must register at the site before you are able to submit your ideas and comments. Although we will consider all of the ideas and comments we receive, we will not respond to them. Since we will moderate the ideas and comments we receive during regular business hours, your ideas and comments may not be viewable immediately. In most cases, your ideas and comments should be viewable within two business days.

Include only information that you wish to make publicly available. Please do not include any personal information, such as Social Security numbers or medical information.

Arthur R. Spencer,
Associate Commissioner, Office of Disability Programs.

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